No. 84-1529

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IN THE

Supreme Court of the United States

October Term, 1985

MARGARET M. HECKLER,
SECRETARY OF HEALTH AND HUMAN SERVICES,
Petitioner,

against

AMERICAN HOSPITAL ASSOCIATION, ET AL.,
Respondents.

On Writ of Certiorari to the United States Court of Appeals For the Second Circuit

BRIEF FOR AMICUS CURIAE, THE STATE UNIVERSITY OF NEW YORK

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Interest of the Amicus

The State University of New York is a legislatively created body, governed by a Board of Trustees, which operates and administers university centers, four year colleges, two year community centers, two year community colleges and other institutions of higher education. See, generally, New York Education Law § 350 *et seq.* Included within the University's system are three major teaching hospitals, two of which contain neonatal units. As an agency of state government, the University is represented here by the Attorney General of New York.

The general interest of the State University arises from its operation of the hospitals within its system, and particularly their neonatal units, where seriously impaired newborn infants have been and continue to be patients and where other hospitals often refer such infants for specialized care. New York regulates, through comprehensive legislation, the conduct of physicians and other health care providers. (N.Y. Public Health Law § 2800 *et seq.* [McKinneys 1977]). Amicus' concern and interest in the issues presented to this Court became direct and immediate in October, 1983, when a newborn infant suffering from multiple and serious congenital birth defects was admitted to the neonatal unit of University Hospital at Stony Brook. That admission resulted in extensive litigation in both the state and federal courts, with the hospital being represented throughout by the Attorney General. The litigation culminated in the decision of the United States Court of Appeals for the Second Circuit in *United States* v. *University Hospital*, 729 F.2d 144 (2d Cir. 1984). That decision was the basis for the Court of Appeals' decision currently under review.

In the State University's view, the decision of the Second Circuit was a correct reading of the intent of Congress and should be sustained. Adopting the position of the federal government would not only sanction an obvious attempt at agency legislation but would be seriously deleterious to the interests of hospitals, doctors, and patients and their families throughout the country.

Accordingly, this brief will demonstrate the harmful effect of the federal government's intrusion into medical

treatment decisions made by the parents of a severely handicapped child in consultation with the treating physician and the effects the challenged regulation would have on the effective provision of health care in the neonatal unit at the University Hospital and other similar health care facilities.

ARGUMENT

Section 504 of the Rehabilitation Act does not authorize federal intervention in medical treatment decisions concerning severely handicapped newborns which are made by parents in consultation with their physicians.

The Secretary of the Department of Health and Human Services ("HHS") argues that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 ("Section 504") permits her to review—and even second-guess—medical treatment decisions of parents of severely handicapped children made in consultation with their treating physicians. The Secretary's simplistic approach to the treatment of impaired infants and her expansive interpretation of Section 504, however, are undermined by the facts of the University Hospital case, the statute itself and its legislative history, and the agency's previous interpretation of Section 504. Moreover, because the regulations implicate constitutionally protected privacy rights, the "exercise of particular care", *United States* v. *University Hospital*, 729 F.2d at 150, is required in determining whether the regulations fall within the Secretary's statutory authority.

A. The Baby Jane Doe Case: *United States v. University Hospital.*

Purportedly acting under the authority of Section 504, the federal government on October 22, 1983 attempted to interfere in the medical treatment being provided to an infant, Baby Jane Doe, at University Hospital's neonatal intensive care unit. The government demanded that the hospital give it access to the infant's medical records. Its asserted purpose was to determine, after a review of the medical records, whether Baby Jane Doe, who was suffering from many serious congenital birth defects, was being "discriminated against by reason of the decision not to provide dual corrective surgeries to the child". (Complaint, ¶¶ 11 and 14).[1] The legal predicate for its request was its view that the hospital's failure to perform surgery on the baby could be discriminatory under the Rehabilitation Act.

1. The Facts.

On October 11, 1983, Baby Jane Doe was born in St. Charles Hospital, Port Jefferson, New York (E. 35). That evening, she was transferred to University Hospital for evaluation of her condition and for possible surgery (E. 36, 41). The attending neurologist examined the child upon her arrival and found that she was suffering from multiple serious congenital birth defects (E. 36-40, 58), specifically,

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1. The complaint was included in the appendix which was filed with the Court of Appeals. The appendix consisted of three volumes, an appendix, a supplemental appendix and a volume of exhibits. A copy of these volumes (which have been bound together) have been lodged with this Court. Page references in this brief prefixed by the letter "A" refer to the appendix; "SA" to the supplemental appendix; and "E" to the volume of exhibits.

myelomeningocele (spina bifida),[2] hydrocephalus,[3] microcephaly,[4] bilateral upper extremity spacticity, prolapsed rectum and a malformed brain stem.

Her parents were fully informed of their child's medical condition and prognosis (E. 41, 52; A. 280-284). They were informed of the risks and potential benefits associated with the two medically acceptable forms of treatment—performing dual surgical procedures or maintaining a conservative medical treatment (E. 41, 51, 53). The record showed, as noted by the Appellate Division, that while the failure to perform surgery would not have placed the infant in imminent danger of death, surgery might have significantly reduced the risk of infection. On the other hand, successful results were also possible with antibiotic therapy. "[W]hile the mortality rate is higher where conservative medical treatment is used, . . . the surgical procedures [proposed] also involved a great risk of depriving the infant of what little function remained in her legs, and would also have resulted in recurring urinary tract and possible kidney infections, skin infections and edemas of the limbs." *Weber* v. *Stony Brook Hospital*, 95 A.D.2d 587,

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2. Myelomeningocele is a failure of the bones surrounding the spinal cord to close fully (E. 36). As a result, the spinal cord and the surrounding membrane protrude from the child's back (E. 82). The effect of this condition on Baby Jane Doe included failure of rectal function; failure of bladder function; very restrictive leg function; and limited sensation (E. 37).

3. Hydrocephalus is fluid in the cranial cavity causing an enlargement of the head (E. 58). This condition, in combination with the microcephalic condition indicates an "extremely high risk for profound and severe retardation . . ." (E. 65).

4. Microcephaly is characterized by an unusually small head and brain at birth (E. 38, 69). The condition is a result of a failure of the brain to form properly (E. 69). As a result, Baby Jane Doe is severely retarded (E. 65).

589 (2d Dep't 1983), *aff'd*, 60 N.Y.2d 208 (1983). After extensive consultation with the treating physicians, family and clergy, the parents decided against the dual surgical procedure and opted instead for the conservative medical treatment (E. 53).

On October 18, 1983, HHS filed a complaint with the New York State Child Protective Service ("CPS") alleging neglect in the care and treatment of Baby Jane Doe. The Child Protective Service, the state agency created by the Federal Child Abuse Protection and Treatment and Adoption Act specifically to explore suspected instances of child abuse and neglect, fully investigated the allegations. It concluded that the complaint was unfounded and that there was no cause for state intervention or further action (A. 290).

On October 16, 1983, immediately prior to the CPS inquiry, a proceeding was commenced in the Supreme Court, Suffolk County seeking appointment of a guardian *ad litem* for the infant and an order directing that surgery be performed. After a trial, the state judge ordered surgery. The New York State Supreme Court, Appellate Division, First Department, unanimously reversed and dismissed the proceeding, finding that the treatment given Baby Jane Doe was medically appropriate:

> It is manifest, therefore, that this is not a case where an infant is being deprived of medical treatment to achieve a quick and supposedly merciful death. Rather, it is a situation where *the parents have chosen one course of appropriate medical treatment over another.* These concededly concerned and loving parents have made an informed, intelligent, and reasonable deter-

> mination based upon and supported by responsible medical authority.
>
> On this record, and in light of all the surrounding circumstances, we find the parents' determination to be in the best interest of the infant. Accordingly, there is no basis for judicial intervention (emphasis added).

95 A.D.2d at 589.

The Court of Appeals of the State of New York affirmed the Appellate Division on different grounds. At the outset, the court stated, "This case involves a situation in which the parents of a new born infant, in consultation with others, had *responsibly* decided upon a course of medical treatment" (emphasis added). *Weber* v. *Stony Brook Hospital*, 66 N.Y.2d 208, 210 (1983). Upon review of the entire record, the court found "no justification for resort to or entertainment of the [state court] proceedings." *Id.* at 213. In particularly harsh language, the court declared, "[T]here are overtones to this proceeding which we find distressing. Confronted with the anguish of the birth of the child with severe physical disorders, these parents, in consequence of judicial procedures for which there is no precedent or authority, have been subjected in the last two weeks to litigation through all three levels of our State's court system." *Id.* at 213. The court found, "[I]t would serve no useful purpose at this stage to recite the unusual, and sometimes offensive, activities and proceedings of those who have sought at various stages, in the interests of Baby Jane Doe, to displace parental responsibility for and management of her medical care." *Id.* at 211.

Finally, the court noted that the New York State Legislature, in enacting the Family Court Act, had made avail-

able a satisfactory procedure to protect children when government intervention is necessary.

> "Article 10 of the Family Court Act is expressly 'designed to establish procedures to help protect children from injury in mistreatment and to help safeguard their physical, mental and emotional well-being. It is designed to provide due process of law for determining when the state, through its Family Court, may intervene against the wishes of the parent on behalf of the child so that his needs are properly met' (Family Court Act § 1011)."[5]

Id. at 211-12.

Notwithstanding the close scrutiny already given to the care of Baby Jane Doe by the state courts and child protection agency, HHS, which was already in possession of at least a substantial portion of Baby Jane Doe's medical records through October 19th,[6] demanded copies of her medical records from the hospital on October 22, 1983. The hospital denied the request, basing its decision, in part, on the fact that the infant's parents had advised the hospital that they did not consent to allow HHS to have access to these confidential records.

On November 2, 1983, the United States filed an action in federal district court to obtain the medical records. After a hearing, defendants were granted summary judg-

5. Pursuant to the Family Court Act, a complaint may be made to the Child Protective Service, which maintains a 24 hour hotline. If warranted after investigation, the CPS may commence a child neglect proceeding seeking immediate court intervention. (N.Y. Family Court Act § 1032 [McKinney 1975]). The court, on its own, may also cause a child neglect proceeding to be commenced.

6. These medical records were not provided to HHS by either University Hospital or Baby Jane Doe's parents.

ment.[7] *United States* v. *University Hospital*, 575 F. Supp. 607 (E.D.N.Y. 1983), *aff'd*, 729 F.2d 144 (2d Cir. 1984). The district court reviewed the record to determine whether University Hospital violated the statute by discriminating against a handicapped person. It found that the parents of the child had refused to consent to the performance of the operation but had instead opted for conservative medical treatment, *id.* at 614-15, that the hospital had been willing at all times to allow the surgical procedures to be performed if the parents would consent to such procedures, *id.* at 614, that the hospital lacked the legal right to perform surgery without the consent of the parents or legally appointed guardian and that the child was receiving medical treatment, including good nutrition, antibiotics and dressing of the spina bifida. *Id.* The district court based these findings on its review of the record in the state court proceedings, including the findings of the New York Court of Appeals and Appellate Division, the conclusion of the Child Protective Service, and the affidavit of the hospital administrator that the child was not being neglected and that the parents had acted responsibly in their choice. On the basis of this factual record the court held that:

> . . . the papers submitted to the Court demonstrate conclusively that the decision of the parents to refuse consent to the surgical procedures was a reasonable one based on due consideration of the medical options available and on a genuine concern for the best interests of the child.

Id. at 614-15.

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7. The trial court entered summary judgment for defendant, despite the fact that defendant did not specifically move for summary judgment, upon the court's finding that no factual dispute existed and that the non-movant was entitled to summary judgment as a matter of law.

Consequently, the court concluded that HHS was not entitled to access to the confidential medical records. It found that the failure of the hospital to perform the surgical procedures in these circumstances was in conformance with its legal obligation not to perform surgery without the consent of the child's legal guardians and "cannot possibly be regarded as a violation of the Rehabilitation Act's prohibition against subjecting a handicapped individual to discrimination solely by reason of her handicap." *Id.* at 614.

The Court of Appeals for the Second Circuit affirmed the lower court's decision. It noted the federal government's principal argument that the lower court erred in concluding that the parents' refusal to consent to surgery conclusively established the hospital's nondiscrimination and thus insulated the hospital from liability under Section 504. The court also noted that the government claimed, for the first time on appeal, that the requested records were necessary to determine whether the failure of the hospital to seek a state court order overriding the parents' decision and compelling surgery was itself a violation of the nondiscrimination requirements of Section 504. Thus, it was clear to the Second Circuit that the government's investigation proceeded on the assumption that the government was empowered by Section 504 to review medical treatment decisions made by parents. Importantly, the Court of Appeals rejected that view:

> . . . in arguing that Baby Jane Doe may have been "subjected to discrimination" the government has taken an oversimplified view of the medical decision-making process. Where the handicapped condition is related to the condition(s) to be treated, it will rarely,

> if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent, breaks down. Beyond the fact that no two cases are likely to be the same, it would invariably require lengthy litigation primarily involving conflicting expert testimony to determine whether a decision to treat, or not to treat, or to litigate or not to litigate, was based on a "bona fide medical judgment", however, that phrase might be defined. Before ruling that congress intended to spawn this type of litigation under section 504, we would want more proof than is apparent from the face of the statute.

729 F.2d at 157.

Finally, the court found that it could not simply presume that Congress intended the federal government to enter the field of infant care, traditionally occupied by the states pursuant to their police power, to oversee judgments historically made by parents and their doctors.

2. The University Hospital Case Demonstrates That HHS's Review Of Treatment Decisions Concerning Handicapped Infants Is Unwarranted And Impedes A Hospital's Ability To Provide Effective Medical Care.

Both the federal investigation into the care of Baby Jane Doe and the HHS regulations are founded on the premise that physician and hospital care for handicapped infants is so callous and deficient as to require federal supervision. As the facts of the Baby Jane Doe case demonstrate, this premise is false. The record before the federal district court in *University Hospital* depicted a hospital with compassionate, competent staff, caring for a

severely handicapped child in accordance with informed medical judgment and the child's best interest. The record demonstrates that the decision as to the course of treatment for the infant was made by the parents in consultation with the treating physician. The hospital was prepared to allow the operations to be performed if requested by the parents.

The experience of University Hospital highlights the effectiveness of the existing comprehensive state scheme for reviewing infant care by trained experts, pursuant to specific statutory and regulatory procedures. The child protective agency and the state judiciary reviewed the care being provided and concluded that it was medically appropriate. Despite prior knowledge of these findings the federal government, without any further evidence, interjected itself into the already settled question of the infant's care. This resulted in severe hardship to the child's parents, the hospital staff and the treating physicians and an unwarranted interference with the effective operation of University Hospital.

If the challenged regulations are permitted to be implemented, these harmful intrusions into the care of children with handicapping conditions will become commonplace. The Second Circuit properly concluded that such broad-ranging federal intrusion should not be permitted except upon an express direction by Congress, based upon its assessment of the policy concerns implicated by allowing the federal intrusion into traditional doctor-patient relationships:

> it is congress, rather than an executive agency, that must weigh the competing interests at stake . . . Until

> congress has spoken, it would be an unwarranted exercise of judicial power to approve the type of investigation that has precipitated this lawsuit.

729 F.2d at 161.

B. There Is No Authority Under Section 504 For The Federal Government To Review Medical Treatment Decisions.

1. Legislative History and Statutory Interpretation.

The legislative history of Section 504 does not support the Secretary's expansive interpretation of that statute. Exhaustive review of the legislative history, the Second Circuit declared, "indicates that congress never contemplated that section 504 would apply to treatment decisions of this nature." *United States* v. *University Hospital*, 729 F.2d at 157. *See also American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. 394, 402 (D.D.C. 1983) (no committee or member of the Congress even suggested that Section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life).

The Court of Appeals, in addressing the petitioner's argument on statutory authorization, noted that:

> [T]he government's theory not only strains the statutory language but also goes well beyond congress's overriding concern with guaranteeing handicapped individuals *access* to programs or activities receiving federal financial assistance. Further, the situation is dramatically different in kind, not just degree, from the applications of section 504 discussed in the legislative history. Under these circumstances, the failure

> of congress to focus on *treatment decisions* involving defective newborn infants strikes a telling blow to the government's position (emphasis added).

729 F.2d at 159-60.

Petitioner relies upon Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000 *et seq.*, to supply for its argument what Section 504's legislative history does not, but this reliance is unavailing. Section 504 was assuredly patterned after Title VI, but there is no indication that Title VI reaches *medical decisionmaking* among alternate treatment options, as opposed to outright denial of equal treatment due to one's status. Petitioner's failure to make this distinction is telling and her reliance upon the dissent in *University Hospital* and the analogy presented therein is therefore misplaced. (Pet. Brief p. 11).[8]

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8. Indeed, the circumstances suggested by Judge Winter which would warrant the invocation of the Secretary's authority under Section 504 are so unlikely to eventuate that they offer little by way of instruction. A decision by a hospital to withhold medical treatment when requested by a handicapped infant's parents simply is unlikely to occur. A refusal to treat at all, upon request, would be a denial of equal access. Petitioner has not cited the Court to one instance in which a hospital receiving federal financial assistance has refused to provide medical treatment to a handicapped infant where the parents had requested it.

The more likely occurrence is the parents' refusal to consent to a particular course of aggressive treatment for their impaired infant. Where medical personnel at the hospital disagree with that determination, they may commence judicial action or contact the appropriate child protection agency. Indeed, this is precisely what occurred with the newborn child with Downs Syndrome who died in Bloomington, Indiana. The hospital sought judicial intervention. The state courts that reviewed the matter, however, determined that the parents had made a reasonable decision among treatment options. The local welfare agency reviewed the case and decided not to challenge the court's order. In a second action brought by the county prosecutor, the court found no parental neglect. *See In re Infant Doe,* No. GU 8204-004A (April 12, 1982), writ of mandamus dismissed *sub nom. State ex rel. Infant Doe* v. *Baker,* No. 4825140 (Ind. May 27, 1982).

A decision by a hospital receiving federal financial assistance not to perform surgery on an individual because of his race raises a question of access based on a proscribed criterion. Such an action by the hospital would clearly be prohibited. Similarly, an action by a hospital to deny admission to a handicapped child solely because the child is handicapped is a violation of the Rehabilitation Act. On the other hand, as the majority's decision noted,

> Where the handicapping condition is related to the condition(s) to be treated, it will rarely, if ever, be possible to say with certainty that a particular decision was "discriminatory". It is at this point that the analogy to race, relied on so heavily by the dissent breaks down.

729 F.2d at 157. The medical treatment decisions which HHS would review if this Court upholds the regulations are likewise related to the handicapping condition itself. HHS's ideological preference for a particular course of treatment does not raise a question of denial of access. To assert otherwise is in essence to argue that Congress had decreed a uniform manner of medical treatment for all impaired infants, irrespective of the judgments of doctors and patients' families. There is not a shred of legislative history or textual support for this proposition.

Petitioner attempts to minimize the obviously disruptive consequences of its expansive reading by conceding that "Section 504 does not provide for 'second guessing of reasonable medical judgment regarding medically beneficial care'" (Pet. Brief, p. 4) and that "[i]n determining whether certain possible treatments will be medically beneficial to an infant, reasonable medical judgment will be

respected." *Id.* Although petitioner argues that "the regulations and guidelines the court of appeals invalidated do not intrude the Secretary into complex medical judgments made by health care professionals", (Pet. Brief, p. 16), the regulations clearly portend the Secretary's interventionist role in determining the reasonableness of any particular medical judgment and imposing her view as to the appropriateness of a particular course of medical treatment. Thus, the regulations provide for the Secretary's expedited access to records and facilities of the recipient hospital for investigative purposes when "necessary to protect the life or health of a handicapped individual." 45 C.F.R. § 84.55(d). There could hardly be a clearer indication that *direct* intervention by the Secretary is foreseen even where the treatment may be based upon the reasonable medical judgment of the primary health care provider.

The Secretary's interest in overriding "reasonable medical judgment" with which the government disagrees is concretely demonstrated by her actions in the *University Hospital* case.[9] When the Secretary attempted to obtain Baby Jane Doe's medical records on November 2, 1983, a guardian *ad litem* had already been appointed to protect the interest of the infant and extensive adversarial proceedings had been completed in state court which approved the reasonableness of the parents' decision.

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9. Petitioner suggests that the Court of Appeals, by issuing a nationwide injunction without waiting for the Secretary to consider the regulation's application in any specific instance, foreclosed her from demonstrating the "flexible" application of Section 504 on a "case-by-case basis, with a sensitive regard for the circumstances presented." (Pet. Brief, p. 15). The Secretary's actions regarding her attempted involvement in the treatment decision of Baby Jane Doe, however, demonstrate her *lack* of sensitivity with regard to the application of the statute.

It is simply disingenuous for the government to argue against this backdrop that it is not seeking to "second guess" reasonable medical judgments or that it would "respect" reasonable medical judgment to select a particular course of treatment for an impaired infant from available alternatives. Congress has not indicated any intent to accord the Secretary the broad and intrusive power she seeks. Unless and until Congress indicates its support for the broad view taken here by the Secretary, there is simply no authority for the Government to override parents' choice of available medical treatment options.

2. HHS's Previous Interpretations of Section 504.

Prior to May, 1982 when the Secretary issued a "notice" to health care providers "to remind affected parties of the applicability of Section 504," HHS, as well as its predecessor, the Department of Health, Education and Welfare ("HEW"), agreed that the statute could not be used as a basis for federal intervention in medical decisionmaking concerning any individual. It was well understood that there was no warrant for federal oversight of medical treatment decisions made by parents of seriously ill infants in consultation with their doctors.[10] Instead, the focus of the agency's original regulations was on the "[a]vailability of

10. In its original notice of intent to issue proposed rules under Section 504, HEW sought comment on certain "critical issues" including whether a regulation should contain provisions regarding a patient's right to receive or refuse treatment. 41 Fed. Reg. 20296 at 20297. Subsequently, HEW concluded "that the department did not have authority to regulate in this area" and that "[t]he Secretary is of the opinion that to promulgate rules on these subjects is beyond the authority of section 504." 41 Fed. Reg. 29548 at 29559.

services" and the accessibility of such services to handicapped persons who desired them. *Id.* at 29567.[11]

As the Second Circuit noted, "[i]t was not until five years later (after the initial regulations were adopted in May 1977) that HHS first took the position that section 504 made it unlawful for hospitals receiving 'Federal Financial assistance' to withhold nutrition, or medical, or surgical treatment from handicapped infants if required to correct a life-threatening condition." *United States* v. *University Hospital*, 729 F.2d at 152. *See also American Academy of Pediatrics* v. *Heckler*, 561 F. Supp. at 397. The court concluded that "HHS's current view of the scope of the statute is flatly at odds with the position originally taken by HEW." *United States* v. *University Hospital*, 729 F.2d at 154.

Petitioner's characterization of the former regulations as supportive of the government's position is simply misleading (Pet. Brief, pp. 2-8, 16-18). The examples cited involve patient access to health care facilities for desired treatment, not the Secretary's involvement in the choice of various treatment decisions made by families and their doctors. Thus, the example of a burn treatment center refusing to treat the burns of a deaf person because of his or her deafness (Pet. Brief, p. 40), *see* 45 C.F.R. Pt. 84 App. A para. 36, illustrates denial of *access* because of one's

11. Under the general provision for "health, welfare and social services," the regulations proscribed denying a qualified handicapped person such services, 45 C.F.R. § 84.52(a), or denying them "the opportunity to participate in or benefit from the aid, benefit or service." 45 C.F.R. § 84.4(b)(1)(i). HHS's analysis of these regulations stressed "the basic requirement of equal opportunity to receive benefits or services." *See* 45 C.F.R. Part 84, Appendix A, ¶ 36. Thus, these regulations recognized the purpose of Section 504—the guaranteeing equal *access* to handicapped persons—and properly excluded review of medical treatment decisions.

handicap. The same is true of the denial of treatment to an alcoholic or drug addict by a federally assisted hospital because of his condition. (Pet. Brief, p. 37). Equating a prohibition of denial of access to medical care because of one's status (*e.g.*, race or handicap) with oversight of medical treatment decisions made by families and their doctors, as petitioner has done, is pure sophistry and mischaracterizes the substance of early regulations.

C. The Damaging Effects of Federal Intrusion Into Private Medical Treatment Decisions.

1. The Regulations Would Prevent Physicians From Exercising Their Professional Medical Judgment In Advising The Parents Of Seriously Impaired Infants.

The challenged regulations, as demonstrated by HHS's actions in the *University Hospital* case, would reverse the normal presumption of validity afforded professional medical judgments. *See Youngberg* v. *Romeo*, 457 U.S. 307 (1982), vacating and remanding, 644 F.2d 147 (3d Cir. 1980). The standard contained in the regulations—whether treatment rendered was "medically beneficial" as determined by "reasonable medical judgments"—would impose a nationwide "negligence" standard upon medical treatment decisions which would predictably lead to federal second guessing and even overriding of the medical judgment of the treating doctors.

Under the regulations, every routine medical treatment decision involving handicapped infants admitted to a re-

cipient hospital has the potential of becoming the subject of lengthy litigation pitting the treating physician against the federal government as to the meaning of a "reasonable medical judgment". Such litigation would undoubtedly subject a hospital's medical and health care services, as well as its physicians and administrators, to intensive and unwarranted scrutiny by unrelated individuals, the media and public officials. In the instance of Baby Jane Doe, University Hospital had to take unusual precautions to protect her privacy and that of her parents, including the assignment of additional security to the neonatal intensive care unit where the infant was located. The hospital was bombarded with telephone calls from individuals seeking information and offering opinions about the treatment of the infant (ranging from an inquiry by Surgeon General Koop, who contacted a member of University Hospital's medical staff to discuss the case, to a request to adopt Baby Jane Doe from an individual claiming to be a well-known movie star).

As a result of these actions physicians were compelled to provide treatment in a fishbowl; the hospital atmosphere became highly charged with suspicions of neglect and medical malpractice. This environment is not only demeaning and potentially intimidating to the responsible professionals, but may actually interfere with their making appropriate decisions relating to medical care. Health care professionals may perform too many, lengthy or expensive tests and procedures, administer unnecessary drugs, or even spend too much time considering available alternatives. This may be harmful not only to the patient in the spotlight but to other patients as well if attention is drawn

away from their needs. Indeed, the federal review of medical treatment decisions could subject handicapped infants to unintended discrimination if, in response to unwise regulation, surgical alternatives are chosen to avoid subsequent claims that "medically beneficial treatment" was not rendered and to prevent litigation over whether "reasonable medical judgment" was exercised.[12]

A courtroom battle between experts over what constitutes medically "beneficial" treatment or "reasonable" medical judgment is precisely what this Court sought to prohibit in *Youngberg* v. *Romeo*. This prohibition is particularly compelling where the judgment as to the appropriate treatment is concurred in by the physician and the infant's parents. The appropriate standard of review should not be more intrusive than whether medical judgment was exercised. Congress did not intend to spawn litigation over the course of medical treatment chosen when it enacted Section 504. *United States* v. *University Hospital*, 729 F.2d at 160.

2. The Regulations Would Displace The Right And Responsibility Of Parents To Make Medical Treatment Decisions In The Best Interests Of Their Children.

In the federal action involving Baby Jane Doe, the United States persisted, in the face of carefully considered decisions by the state courts, the state child protective agency, the treating physicians, and most importantly, the loving and concerned parents, in attempting to impose

12. For example, if Baby Jane Doe had been forced to undergo immediate surgery for the spina bifida she might have lost all function in her legs. (E. 74).

its view that Baby Jane Doe's spina bifida must be treated with surgery. The invalidated HHS regulations would permit innumerable repetitions of such harassment.

This Court has recognized that parents, in making difficult treatment decisions involving their children, will presumably act in the best interests of those children. In the absence of a showing of abuse, that presumption should be respected. *Parham* v. *J.R.*, 442 U.S. 584 (1979). The invalidated regulations would require that health care providers always seek to impose an aggressive course of medical treatment as being in the best interest of the child. *Ipso facto,* such a mechanical rule would often times override parental treatment decisions made after consultation with their physicians.

The parents of Baby Jane Doe, who were subjected to an investigation by the child protective agency and to litigation through all three levels of both state and federal court, were consistently found to have been acting in the best interests of their child, in selecting a conservative course of medical treatment. They chose, relying on the sound professional judgment not to authorize an operation to close the spina bifida lesion, but instead to have it dressed surgically. By mid-December 1983, the spinal defect had closed spontaneously without surgical intervention vindicating their decision. *See* Baby Jane Doe at Stony Brook: A Chronology; Treatment of Newborns: Medical, Ethical and Social Issues. State University of New York at Stony Brook; October 17-20, 1984, p. 3.

Conclusion

The decision of the United States Court of Appeals invalidating the proposed HHS regulations should be affirmed.

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Respectfully submitted,

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